The approval of drugs "specific" for myelodysplastic syndromes and the recent acquisitions in terms of pathophysiology prompted renewed interest for this group of diseases. Thus, in a climate of novel therapeutic options and improved diagnostics, the Ninth International Symposium on Myelodysplastic Syndromes took place in Florence, last May.

The attendees were 1450, from 62 countries around the world, making Florence meeting the most crowded of the Symposia held until now and dedicated to Myelodysplastic Syndromes. This enthusiastic attendance was well reflected by the fact that the Auditorium and all the Sessions were well populated by hematologists who animated lively discussions and raised burning questions. Of course this energetic participation was driven by the possibility of applying new therapeutical agents and by the consequent need to focus the exact clinical targets.

For the first time, an International Nurse Forum preceded the Symposium, on May 15th. The Forum “A New Chapter in MDS: Turning the Page from Hopelessness to Hope” included contributions from physicians and nurses and was addressed to introduce the complexity of myelodysplastic syndromes to nurses, but also to discuss the practical aspects of administration of new drugs, as well as to reflect upon the special relationship among MDS patients and attending nurses. We look forward to the Second Nurse Forum in 2009!!

During the Opening Session, chaired by P. Greenberg and M. Tomonaga, three lectures updated on epidemiology, diagnostic classification and cytogenetics of myelodysplastic syndromes. These outstanding lectures set the pace for the quality of the entire Symposium. The Susanne Fleishman Memorial Lecture introduced by John Bennett, closed the opening session, with T.E. Quill, interest specializing in palliative care, addressing the important topic of decision sharing and communicating with MDS patients.

Another novelty of the Florence Symposium was the "Tito Bastianello" Award, instituted by Mrs. Francesca Bastianello, in memory of her husband, affected by MDS, to promote and support research on MDS. Mrs. Bastianello awarded five young investigators who presented the best contributions to the Symposium. The day ended in the wonderful courtyard of Palazzo Pitti, where everybody enjoyed Florentine food and wine.

The first day of the Symposium was dedicated to the pathophysiological aspects and interesting data have been presented.
regarding gene expression signatures in different MDS subtypes, with particular regard to 5q- syndrome, as well as molecular and immune defects, alterations in signal transduction and the very much needed MDS animal models. Later on during the day, clinical results and perspectives in the use of azacitidine and lenalidomide were the subject of two mini-symposia. Azacitidine associations with histone deacetylase inhibitors, anti CD33 antibody and thalidomide have been discussed, both from the biological and from the clinical point of view. Setting up optimal drug association and optimal scheduling should help us acquire better results in MDS treatment, and, in the case of azacitidine plus histone deacetylase inhibitors, if preliminary results from G. Garcia Manero are confirmed, it should become standard therapy.

For lenalidomide, its outstanding activity in 5q- syndrome was strongly confirmed with new data, but G. Mufti developed the issue of this specificity, while A. List and A. Giagounidis clarified the best theoretical and practical management of lenalidomide in the treatment of MDS with 5q- isolated or combined to other anomalies. Lenalidomide possible significant activity in non 5q- MDS was also matter of debate. Simultaneous sessions were centered on immunological pattern and anomalies in MDS and on the involvement of mesenchimal and dendritic cells in these pathologies.

On May 17th, the Symposium opened with three lectures in which other myeloid neoplasms than MDS were considered as model to help our understanding of molecular and biological mechanisms at the basis of altered haematopoiesis (PNH, MPD, and AML). The day then went on with a stimulating revision of diagnostics in myelodysplastic syndromes, in a dedicated plenary session and extremely energetic simultaneous sessions. The need for diagnostic tools supplementary to morphology, like flow cytometry analysis, molecular markers detection and identification of possible new prognostic tools was the matter of a rich debate. In particular, L. Malcovati confronted the audience with the new WPSS prognostic scoring system, in which transfusion need in the course of MDS is considered a prognostic parameter. Following this line, the impact of iron overload in the natural history of transfusion dependent MDS was thoroughly analyzed in a mini-symposium and in a number of posters. The importance of iron chelation and of appropriate targeting of patients suitable for iron chelation was presented by N. Gatterman. The existence of a recently approved oral iron chelator makes extremely actual this previously neglected issue in the management of MDS.

To end, three sharp lectures updated on growth factors background (R. Invernizzi) and practical use in the treatment of MDS: E. Hellström-Lindberg clarified the optimal management of erythropoietin plus granulocyte colony stimulating factor, while D. Bowen discussed new ways to approach neutropenia and especially thrombocytopenia, with the new agent AMG 531.

On Saturday, May 19th, in a still crowded Auditorium, the evidence-based hematology regarding myelodysplastic syndromes was presented. This was an original style to conclude the Symposium and summarize the data of last years research and of clinical results.

The different profiles of the ideal MDS patients candidate to be best responders to each of the therapeutical options available at present were discussed: growth factors, chemotherapy both low and high dose, the so-called epigenetic therapies: demethylating agents and histone deacetylase inhibitors, and bone marrow transplantation. The lectures of the day were meant to provide a sort of practical, reasoned “passé partout” to MDS treatment, which T. de Witte lively concluded.

After the closure of the Ninth Symposium, Saturday afternoon, MDS patients gathered in Palazzo dei Congressi, for an intense Patient Forum, the first of its kind in Italy, generously animated by a “not jet exhausted” Kathy Heptinstall.
This year has flown by! It seems that we were just starting 2007 yesterday and now we are once again in the throes of completing work on the functions that we will conduct during the ASH (American Society of Hematology) Annual meeting. Our Friday December 7th Friday Symposium—Changing the Characterization of MDS: Diagnosis to Therapy marks a decade of successful adjunct symposia at this important meeting. This meeting is chaired by Dr. Stephen Nimer of Memorial-Sloan Kettering in NYC and has a preeminent Faculty.

In addition to the Symposium we will again conduct a reception honoring the recipients of the 2007 Young Investigator Awards and we will be conducting our first “MDS Foundation Reception” at Turner Field in Atlanta. This will be an informative and fun evening on Sunday, December 9. If you would like to attend please contact us at the Foundation’s Booth and learn how to earn your ticket.

The Foundation has continued to broaden our reach to patients and physicians in 2007. Two of the meetings are highlighted in this newsletter but these are only the tip of the iceberg! One of our staff members suggested that we look at where in the world the booth has been to make our MDS Foundation Booth and materials the ‘Flat Stanley’ of MDS education and information! So where have we gone to educate patients and healthcare providers about MDS?

During February and March we conducted Patient Forums in Freiburg, Germany; Seattle, Washington; and Duarte, California. These were highly successful and helpful to our many patients and support persons who attended them. Drs. Michael Lübbert, Joachim Deeg, and Mark Kirschbaum spoke to the patients and their caregivers about MDS and the hope that new treatments are bringing to patients.

In March 2007 the Foundation and our booth traveled to Punta del Este, Uruguay to participate in the ISH meeting for Latin and South America. The response of physicians from these countries was astounding! We provided information in English, Spanish, Portuguese, and even Japanese to attendees! At the end of the first day there was literally nothing left of the thousands of pieces of information we took to this meeting.

We conducted our first nursing symposium at the Oncology Nursing Society’s Annual Meeting in Las Vegas, Nevada to a standing room only audience. Serving as Faculty for this event were Sandy Curtin, Jeanne Ridgeway, Kathleen Weaver of the MDS Foundation, Lew Silverman, MD and Erin Demakos. Since then we have distributed hundreds of copies of this symposium on CD ROM to nurses worldwide.

The British Society of Hematology meeting in Bournemouth, England followed quickly. This marked our 4th year of participation in this UK-wide meeting. We moved to London from Bournemouth and conducted a Patient Forum for the UK MDS group. This forum will form the basis for a UK-wide Patient Support Group. Drs. Ghulam Mufti and Sally Killick provided information and answered questions for the attendees and their families.

For the fifth year we participated in the BIO 2007 Conference. This year it was held in Boston, Massachusetts. It is here that we make contact with companies conducting research in MDS and other patient advocacy groups from around the United States.

The 9th International Symposium on MDS was held in Florence, Italy on May 16 –19 and attracted more than 1450 participants. Please read the editorial in this addition by Dr. Valeria Santini outlining the outstanding symposium. We congratulate Professor Mario Cazzola and his Scientific Committee on presenting what might be the best MDS meeting ever held! In addition to the full scientific meeting we conducted a Nursing Forum and a Patient Forum as adjunct meetings. Both were extremely well attended and greeted enthusiastically by the participants.
The American Society of Clinical Oncology (ASCO) was the next ‘stop on the road’ for our booth and information. This was once again a very successful meeting for distributing the Foundation’s many educational and information pieces for patients and physicians. The interest in hematologic malignancies is growing every year in what was previously thought of as a solid tumor-oncology focused meeting. At the end of June we conducted a Patient Forum in conjunction with Mayo Clinic and Dr. David Steensma. This was a very well attended meeting that benefited these Minnesota patients and their families.

I had the privilege of participating in a meeting for hundreds of physicians from all over Russia to educate them on MDS, its diagnosis and new treatments and on the needs of patients living with MDS. This coincided with the approval of decitabine (Dacogen) in Russia. Our Patient Handbook and Iron Overload Handbook have now been translated into Russian for use by patients in this enormous country. The need for information was apparent in this group of physicians as evidenced by their active and attentive participation in both the plenary and breakout segments of this meeting.

We presented our third consecutive symposia as well as our booth and information at the European Hematology Association’s Annual Meeting in Vienna, Austria. The well attended symposium and influx of visitors to our booth for information in the many languages of Europe make this a busy and extremely worthwhile meeting each year. We look forward to our participation in 2008!

We conducted patient forums in Baltimore, Maryland; Dubrovnik, Croatia; and Sinaia, Romania in September and October. In addition, during this time period the Foundation participated in the XXIII Symposium of the IACRLRD in Freiberg, Germany and the Leukemia/Lymphoma meeting in Dubrovnik. Please read the synopsis of these meetings written by our US Patient Liaison, Audrey Hassan.

We also presented the booth and materials to participants in the ISH–European and African segment in Budapest, Hungary and to the ISEH Congress in Hamburg, Germany.

On September 28 and 29th the Foundation participated in the first MDS Symposium to be held in South America. The meeting was conducted in Fortaleza-Ceará, Brazil and was hosted by many of the Brazilian physicians we have come to know over the years including Drs. Luiz Fernando Lopes and Silvia Magalhães. More than 100 patients attended their Patient and Family Forum. The attendance at these meetings clearly demonstrates the needs that patients and families have for support and information everywhere in the world.

In late October, Jean Goasguen (Rennes, France) and John Bennett (our Chairman) conducted a “first of its kind meeting” in New Orleans, Louisiana for the American Society of Clinical Pathology. Attendees were provided with a new method of learning about MDS morphology through an innovative program called Virtual Microscopy. This was the inaugural session of a six-part series on MDS morphology which will allow hematopathologists and others who interpret MDS pathology as part of the intricate and important process of diagnosing and categorizing MDS patients to earn an Expert in MDS Morphology designation from the Foundation. Please read the announcement in this edition of the newsletter and join us online to participate in this important CME program.

Following that meeting, we held the initial gathering of the International Working Group on MDS Cytogenetics. We will keep you up to date as this group begins its important work focused on better defining cytogenetics in MDS.

Last month we attended the 4th International Congress on MPD and MDS in New York City, hosted by Dr. Richard T. Silver of Weill Medical College of Cornell University, New York, NY.

Now ASH is, as I noted at the beginning, here again. The Foundation has made, in 2007, great inroads into spreading the word about MDS, educating physicians worldwide, engaging nurses worldwide in this process, and helping patients everywhere in living with MDS. 2008 is shaping up to be just as busy with events planned through ASH 2008 in San Francisco! These include some of the same events but also new ones. We are planning the next MDS Foundation Golf Tournament benefiting our Young Investigator Grant Program in Tampa, Florida on February 18. This tournament is a one fundraiser each year and is being conducted for the second year in conjunction with the H. Lee Moffitt Cancer Center in Tampa.

We will conduct our first satellite symposium at the European Oncology Nursing Society and will once again participate with the Groupe Français des Myélodysplasies in their biannual meeting. The Foundation also hopes to participate in the first National Update on MDS that will be held in July in Mumbai, India and has accepted the task of presenting a symposium on MDS during the ISH 32nd World Congress in Bangkok, Thailand.

In addition to these endeavors we are pleased to announce that we will hold our first US-wide and EU-wide Patient and Family Forums in early fall of 2008.

I would like to thank our supporters on behalf of the Foundation and its Board of Directors. These supporters, first and foremost, are the MDS patients, their families and friends, who form the core of this Foundation. You are our center and the reason that the Foundation exists. We work for you!

The second group that we would like to thank are the pharmaceutical companies that provide us with so much support and assistance. This assistance is given in the form of grants that fund programs that are non-product related but, rather, are geared toward improved disease knowledge and patient support. We could not do the work we do without this type of support.

From all of us at the Foundation, I wish you a wonderful Holiday Season and a Happy New Year!
**MDS Young Investigator Grants Program**

**Foundation Awards Grants**

**THE YOUNG INVESTIGATOR GRANT PROGRAM FOR FELLOWS IN HEMATOLOGY**

In December 2005 The Myelodysplastic Syndromes Foundation, Inc., initiated a series of grants “The Young Investigator’s Grant Program for Fellows in Hematology”. These awards are granted annually.

The Grant Review Committee selected Klas Raaschou-Jensen’s grant submission entitled “Identification and Characterization of the Genetic Background in a Unique Danish Family with Several Cases of Hypoplastic Myelodysplastic Syndrome” and Azim Mohamedi’s submission entitled “Prevalence and Pathogenetic Significance of Uniparental Disomy on Chromosome 4q in RARS” as the two Young Investigator Grant winners.

**The 2008 Recipients Are:**

- **Azim Mohamedi, PhD**
  Kings College London
  London, United Kingdom

- **Klas Raaschou-Jensen, MD**
  Copenhagen University Hospital, Rigshospitalet
  Copenhagen, Denmark

The Foundation is dedicated to furthering the research into MDS and invites Young Investigators (under the age of 40) to submit either basic or clinical research proposals into the causation, epidemiology, molecular biology, cytogenetics, morphology, prognosis, or management of the Myelodysplastic Syndromes.

**THE YOUNG INVESTIGATOR GRANT PROGRAM**

**is supported by this year’s**

**MDS Foundation-H. Lee Moffitt Cancer Center Golf Tournament for MDS:**

**February 18, 2008**

**Platinum Sponsors:**

- **Cyanogen**
- **MC1**
- **Pharmion**
- **Novartis**

**Silver Sponsor:**

- **Genzyme**

**Bronze Sponsors:**

- **MDS Foundation**
- **Moffitt**

The application deadline for 2009 grants is June 15. Notification of the awards will occur by October 1, 2008 with activation on January 1, 2009.

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**NEXT YEAR’S TIME LINE**

**Proposals Due:** Friday, August 15, 2008

**Notification of Awards:** Wednesday, October 1, 2008

**Award Ceremony:** Friday, December 5, 2008

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**Save the Date for the Second Annual MDS Foundation-H. Lee Moffitt Cancer Center Charity Golf Tournament for MDS**

Presented by Bruce Fleisher (PGA Champions Tour Professional)

**Clear your calendar... the date is set!**

February 18th, 2008 will mark our 2nd Annual Charity Golf Tournament to be held at Innisbrook Golf Resort. You are cordially invited to be a part of the Gallery for this important charity event. The proceeds from this tournament will be donated to The (continued on next page)
Pharmion has provided the MDS Foundation with an educational grant to support the Foundation’s work.

Interested players and sponsors are invited to contact the MDS Foundation at:

1-800-MDS-0839
Email: kweaver@mds-foundation.org
or visit our golf website at www.mdsgolftournament.golfregistrations.com

Young Investigator’s Grant Fund for Fellows in Hematology that will provide resources to further the research of MDS and hopefully, to one day find a cure. Look for future announcements and invitations with more specific information as the time nears. And don’t forget to practice!

**Special events include:**
- Celebrity Pairing Party—a chance to mix and mingle with the participating celebrities and PGA Champions Tour Professionals
- Clinic and Small Group Instruction with the Pros
- Awards Dinner and Live Auction (including fabulous golf packages with some of the top players on the Champions Tour!)

**Foundation Initiatives for 2008 and Beyond…**

The MDS Foundation is committed to making a significant contribution to the advancement in understanding and of accurately diagnosing the myelodysplastic syndromes. We will be focusing our efforts in the following initiatives:

- **ADOPT REGISTRY**

  Sponsored by a grant from: genzyme

- **PATIENT QUALITY-OF-LIFE FORUMS**

- **WORLDWIDE PATIENT SUPPORT GROUPS**

- **10TH INTERNATIONAL MDS SYMPOSIUM, PATRAS, GREECE:**
  May 6–10, 2009

**MDS Essentials E-Newsletter**

The Foundation has created a new electronic E-Newsletter to provide healthcare professionals and patients from around the world with timely information, in a cost-effective manner. The MDS Essentials E-Newsletter is the electronic version of our quarterly newsletter. Receive up-to-date information on clinical trials, research and news by simply subscribing online at:


**ADDITIONAL PROGRAMS**

- Differentiating Anemia (CME Program)
- MDS Practice and Treatment Survey
- The International Working Group on MDS Morphology
- Transfusion Burden Registry
- The International Working Group on MDS Cytogenetics
- The International Working Group on Quality of Life in MDS

**CME AWARENESS PROGRAM**

Understanding MDS: A Primer for Practicing Clinicians

Visit www.mds-foundation.org and click on The MDS Foundation Resource Center to take advantage of this comprehensive program, and other informative programs coming soon, designed to provide you with tools and information that will assist you in administering the best care to your patients.

The first four segments of this eight segment series are currently available:

Segment 1: The Past & Present in MDS
Segment 2: Clinical Presentation, Diagnosis & Pathology
Segment 3: Ineffective Hematopoiesis: Considerations in Diagnosis and Treatment
Segment 4: Anemia in MDS: Survival, QoL, and Treatment Options

COMING SOON!

Written programs are available in Spanish, French, Italian, German and Japanese.

- CE Awareness Program for Nurses
- CE Awareness Program for Pharmacists

Sponsored by grants from:

[Pharmion logo]

Pharmion has provided the MDS Foundation with an educational grant to support the Foundation’s work.
Meeting Highlights and Announcements

**MDS Mission for Nursing Education**

**Educational Symposia held in Las Vegas, Nevada and Florence, Italy**

**MDS Satellite Symposium held at the Oncology Nursing Society (ONS) 32nd Annual Congress**

The MDS Foundation was pleased to participate in the ONS annual meeting held this year in Las Vegas where we presented the Foundation’s first symposium in conjunction with ONS. Our Satellite Luncheon Symposium—Clinical, Communication, and Coping Knowledge: The Keys to Helping MDS Patients on Their Journey to Hope—was held on April 24th, 2007 at the Mandalay Bay. More than 300 nurses gathered for this meeting making the Foundation’s first nursing adjunct symposium a great success. Our booth was extremely well attended and nursing colleagues from across the country joined us to learn more about MDS and their treatments.

Our distinguished faculty included Lewis Silverman, MD (Mt. Sinai Medical Center in New York City), Erin Demakos, RN, CCRC (Mt. Sinai Medical Center), Sandy Kurtin, RN, MS, AOCN, ANP-C (Arizona Cancer Center, Tucson), and Kathleen Weaver, Grant and Funding Director for the MDS Foundation. Topics included Managing MDS Patients: The Physician Perspective, Low-Intermediate 1 and High Risk Case Presentations, and What did we hear? What issues are patients/families dealing with? Information developed from the 28 Patient and Family Quality of Life Forums that have been held around the world formed the basis for this meeting.

For your free CD ROM containing all of the slide presentations from this symposium, please contact the MDS Foundation at 1-800-MDS-0839.

**MDS CE Nursing Forum held at the 9th International Symposium on MDS**

The CE Nursing Forum entitled A New Chapter in MDS: Turning the Page from Hopelessness to Hope was held immediately preceding the 9th International Symposium on MDS. At a five-hour symposium held on May 15th, 2007, the Presenters imparted information on improving communication with patients, allowing clinicians to better understand and appreciate the impact of an MDS diagnosis, the thought processes that physicians face in diagnosing MDS patients, conveying that diagnosis to patients and family members, and evaluating the impact of MDS specific management approaches and treatments.

**FEATURED TOPICS AND FACULTY**

- An Update on Research into MDS Therapies
  David Bowen, MD
  The Leeds Teaching Hospitals, Leeds, UK

- Managing MDS Patients: The Nursing Perspective
  Erin P. Demakos, RN
  Mt. Sinai School of Medicine, New York, NY

- Essentials in Understanding: How Do We Determine Patient and Family Needs
  Barbara Deschler, MD
  University of Freiburg Medical Center
  Freiburg, Germany

- The MDS Foundation and the Journey to Hope
  Kathy Heptinstall, RN
  The MDS Foundation
  Crosswicks, NJ

- Managing MDS: Current Strategies and Standards
  Valeria Santini, MD
  University of Florence
  Florence, Italy

- What are the Myelodysplastic Syndromes: Understand a Difficult Disease
  Norbert Vey, MD
  Institut Paoli-Calmettes
  Marseille, France

Dr. Radu Gologan from Fundeni Clinical Institute, Bucharest, Romania makes a visit to the MDS Foundation office in Crosswicks, New Jersey on November 8th.
The XXIII Symposium of the International Association for Comparative Research on Leukemia and Related Diseases

September 7–11, 2007
Freiburg, Germany

From Molecular Pathogenesis to Targeted Therapy in Leukemia and Solid Tumors

The 23rd Symposium of the International Association for Comparative Research on Leukemia and Related Diseases (IACRLRD) was held September 7–11, 2007 in Freiburg, Germany. This is the oldest international association and the meetings are held bi-annually. The venue was the University of Freiburg, Dr. Roland Mertelsmann the Symposium President. Roughly 300 participants consisting of internationally renowned physicians and research investigators along with young scientists attended the sessions which focused on the status quo and the future of targeted therapies. A summary of the program and other information is available at www.IACRLRD.de.

The strong scientific focus of the Meeting was the update on targeted therapies in myeloid leukemia, preleukemias including MDS and myeloproliferative syndromes, lymphoid malignancy and solid tumors. Numerous speakers presented exciting bench-to-bedside results on epigenetic therapy approaches both in MDS and in the biological and therapeutic continuum of high-risk MDS and acute myeloid leukemia, e.g. in older AML patients in whom intensive chemotherapy is not a meaningful option (reduced performance status, comorbidities etc.). The “targeted therapy” approach of the antiangiogenic agent lenalidomide in 5q- MDS patients provided a new and exciting paradigm for a rational therapy in a distinct MDS subtype based on a specific chromosomal aberration.

On Monday, September 10th the sessions on MDS were held. Chairs: N. Gattermann, Düsseldorf and M. Lübbert, Freiburg. Topics and faculty included:

- H. Phillip Koeffler, USA:
  From chromosomal losses to SNPs and epigenetic silencing: Molecular pathophysiology of MDS and myeloid leukemia

- Steven Gore, USA:
  Emerging treatment options in high-risk MDS

- Aristoteles Giagounidis, Germany:
  Modulation of angiogenesis in MDS: Clinical results

- Jürgen Finke, Germany:
  Curing MDS—Allografting options anno 2007

Foundation members Drs. Elihu Estey, Houston, Texas; Mark Kirschbaum, Duarte, California; and Valeria Santini, Florence, Italy were presenters as well during the 5-day sessions. Members of the Foundation were also well represented on the Scientific Committee:

- S. Amadori, Italy
- S. Gore, USA
- E. Hellström-Lindberg, Sweden
- H. P. Koeffler, USA
- B. Labar, Croatia
- C. Niemeyer, Germany
- S. Nimer, USA
- M. Sanz, Spain
- T. de Witte, Netherlands

The University of Freiburg served as the venue.
Dr. H.P. Koeffler, USA during his presentation.

Chairmen: Drs. N. Gattermann, Dusseldorf and M. Lübbert, Freiburg.

Dr. Lübbert expressed his pleasure that the Foundation could participate. One of the highlights of the social program was a tour of the world’s third largest winery, Badischer Winzerkeller (Breisach), complete with a wine tasting that was sponsored by a very grateful patient of Dr. Lübbert’s.

Dr. Clara Bloomfield assumed the presidency of IACRLRD during the meeting. The next symposium, in 2009, will be held in Columbus, Ohio and hosted by The Ohio State University Comprehensive Cancer Center.

Future symposia highly recommended are the EBMT meeting to be held in Florence, Italy in March 2008. It is anticipated that 4000 will attend with one entire day dedicated to MDS patients. Kathy Heptinstall, Operating Director of the MDS Foundation, will serve as Co-chairman of this Patient and Family Day. Another is the joint Annual Meeting of the German, Austrian and Swiss Societies of Hematology and Oncology (DGHO, OGHO, SGMO), taking place in Vienna, Austria, in October 2008.

Social Program
Badischer Winzerkeller Winery (Breisach)
Sponsored by MDS patient, Mr. Alfred Wagner, pictured above with MDSF staff members Nancy Mrzljak and Audrey Hassan; and Dr. Lübbert.

Dinner in the Black Forest.

Dr. Lübbert extending a warm welcome.

Dr. Bloomfield, IACRLRD President, toasting Dr. Lübbert.

Leukemia and Lymphoma Symposium
September 15–19, 2007
Dubrovnik, Croatia

East and West Together

A prestigious group of hematologists and experts in MDS attended this meeting. Drs. Cazzola, Cermak, de Witte, Greenberg, Hellström-Lindberg, Hoelzer, List, and Malcovati from the MDS Foundation were among this group.

On Sunday, September 16th the sessions on MDS were held. Chairs: P.L. Greenberg, USA; T. de Witte, The Netherlands. Topics and faculty included:

- P.L. Greenberg, USA:
  Classifications of myelodysplastic syndromes: recent advances
- L. Malcovati, Italy:
  Transfusion dependence and iron overload and prognostic modeling of MDS
- E. Hellström-Lindberg, Sweden:
  Low-risk MDS—do we need more than supportive care?
- M. Lübbert, Germany:
  Epigenetic therapy in the biological continuum of MDS and AML
- T. de Witte, The Netherlands:
  Stem cell transplantation (SCT) for MDS
- A.F. List, USA:
  New therapeutics for myelodysplastic syndromes
- M. Mistrik, Slovakia:
  Myelodysplastic syndromes management in Slovakia

(continued on next page)
Our patient forums continued in Europe with the Foundation’s first patient forum held in Croatia on September 13th. Our speakers included Prof. Drs. Ranka Serventi-Seiwerth, Drago Batinić, and Sandra Basić-Kinda. The forum was conducted in conjunction with the Croatian Association of Leukemia and Lymphoma Patients.

Accurately enumerating blast cells, essential for prognostic assessment and treatment stratification of MDS, is often difficult, due to imprecise criteria for the morphological definition of blasts and promyelocytes. The diagnosis of early stages of MDS is also problematic, due to a lack of minimal diagnostic criteria.

The French-American-British (FAB) Classification system served as the standard for MDS classification for two decades and still provides considerable prognostic/diagnostic information. The International Prognostic Scoring System (IPSS) provides a prospective risk assessment from the initial diagnosis but is dependent on having both an accurate bone marrow blast assessment and cytogenetic analysis. Increasing blast percentages (5–10, 1–20, 20–30) increase the risk of death from all causes and leukemic transformation. The World Health Organization (WHO) proposed a revision to the FAB morphologic approach. These revisions included lowering the threshold for the percentage of blasts required to make...
the diagnosis of AML from 30% to 20%.

All of these classification systems depend critically on an assessment of dysplastic changes in the marrow and the percentage of marrow blasts to stratify patients. It is assumed that the blast definitions described by the FAB system are being used uniformly by hematologists/pathologists worldwide, and that blasts could be identified and counted very easily. In actual practice, however, this is not the case.

In 2003, an International Working Group (IWG) of hematopathologists, hematologists and experts in the field of MDS reviewed the morphological features of bone marrows from all the subtypes of MDS and agreed on a set of recommendations. This multi-segment CME program is intended to assist pathologists in becoming experts in the classification of MDS patients.

At the end of this series, participants will understand the need for morphologic expertise in the classification of MDS; understand the methodology/validation used to develop new cell definitions in MDS, understand the changes in cell definitions suggested by expert concordance, and have the ability to effectively complete the full CME program utilizing virtual microscopy.

To receive program informational materials please call 1-800-MDS-0839 or register online at www.mds-foundation.org.

**MDS in Saudi Arabia**

**November 13–15, 2007 Riyadh, Saudi Arabia**

On November 13–15 the MDS Foundation was privileged to participate in the International Congress on Bone Marrow and Stem Cell Transplantation in Riyadh, Kingdom of Saudi Arabia. We participated with support from Novartis Oncology and at the personal invitation of Drs. Hassan El-Sohl (Chairman of the Organizing Committee) and Dr. Mahmoud Aljurf (Chairman of the Scientific Committee) of King Faisal Specialist Hospital and Research Center.

The Organizing Committee anticipated that 600 to 700 nurses and physicians would attend this meeting. The reality was more than 1400 attendees! The participants included HSCT and hematology leaders from Africa, Asia, and Eastern Mediterranean countries. In addition to the main scientific forum an entire day was devoted to a nursing forum for nurses working in HSCT. The topics covered stem cell biology, acute leukemia chronic myeloid malignancies, lymphoid malignancies, bone marrow failure and hemoglobin disorders, immunodeficiency, cord blood transplants, GVHD, infections in transplant and translational research.

With the huge unanticipated attendance everyone at King Faisal worked ‘overtime’ to insure that this meeting was flawless. Our experience was certainly that—flawless! The scientific sessions were excellent and many people from around the world participated as members of both the Scientific Program Faculty and the Nursing Forum Faculty for this program.

We were also treated to wonderful meals and an opportunity to see Riyadh as it existed 50 years ago. The transcendence of this truly cosmopolitan city from the rural farming based community of 40 years ago to the metropolitan and technologically advanced area that it is today is truly remarkable.

The Foundation’s booth was welcomed with open arms by the participants and we came home empty handed from this meeting with many requests for information to fulfill following the meeting. On behalf of the Foundation I would like to thank everyone who assisted us so readily during our visit! This was a remarkable meeting run by a group of remarkable people who truly put Riyadh and King Faisal on the ‘map’ of key hematology and bone marrow transplant centers worldwide.

![Maha Sabbagh of Novartis Oncology and her Saudi Arabian colleagues.](image)

![The Head of Public Relations from King Faisal.](image)

![Dr. Aljurf (right) and one of the Symposium attendees.](image)

![The wonderful Public Relations group who made our stay and the meeting memorable.](image)
Myelodysplastic Syndromes—Innovations, Understanding and Advances

The Myelodysplastic Syndromes Foundation presented its second adjunct symposium at The European Hematology Association 12th Annual Meeting in Vienna. The symposium was greeted by standing room only, 1000 copies (on CD-ROM) were distributed on Friday and Saturday of the EHA meeting. This educational video and the accompanying slides will be provided to audiences both via our Educational website and on CD for continued use throughout 2007. Translations of educational materials in Czech, Dutch, French, German, Greek, Hungarian, Italian, Japanese, Polish, and Spanish were also provided free of charge at our booth.

For a copy of the CD ROM, which contains all of the slide presentations from this session, please contact the MDS Foundation at 1-800-MDS-0839.

AGENDA

- Introduction: Ghulam J. Mufti, MD
- Growth Factors: Impacting Survival in MDS? Eva Hellström-Lindberg, MD, PhD
- MDS Prognosis—Unveiling a Real-Time Assessment Tool: Luca Malcovati, MD
- The Role of Reduced-Intensity Regimens in High-Risk MDS: Decision Guidelines Theo J.M. de Witte, MD, PhD
- Epigenetic-Basis for Treatment in MD Jean-Pierre Issa, MD
- Current Revisions to WHO: Clinical Implications John M. Bennett, MD
- Summary and Q&A Pierre Fenaux, MD

Learn More About MDS: Join the Journey to Hope for MDS

- MDS is a puzzling, life-threatening group of diseases of the bone marrow for which there are no easy cures or quick remedies.
- The most common of all the cancers related to the blood system, it is estimated there are more than 30,000 new MDS cases each year in the United States alone. We believe this is vastly underestimated.
- Despite more than three decades of dedicated research, the causes of MDS remain largely unknown.
- MDS is largely unknown to the general public.
- For roughly 30% of the patients diagnosed with MDS, these diseases will progress to acute myeloid leukemia (AML), a type of bone marrow malignancy which does not respond well to chemotherapy.
- Until recently treatment consisted only of supportive care including blood transfusions (red blood cells or platelets), and treatment with growth factors like erythropoietin (EPO) with G-CSF or GM-CSF. There are now three drugs approved for the treatment of MDS: Vidaza® (azacitidine), Dacogen® (decitabine), and Revlimid® (lenalidomide). At present, there are two FDA-approved drugs for the treatment of transfusion-dependent iron overload: Exjade® (deferasirox) and Desferal® (deferoxamine). None of these are curative.

How to Help:

- Bone marrow transplantation is often the only chance of survival. Nearly 70% of the patients are without a match. The need is especially critical in racial and ethnic minority groups.
- As a not-for-profit organization, the MDS Foundation depends entirely on public funding in the form of individual gifts, donations from individual and corporate entities, and membership fees to further our work.
- To learn how to support the MDS Foundation, go to the Foundation’s website at www.mds-foundation.org.
Foundation Plans International Symposia Through 2013

The MDS Foundation has approved applications for the next three International Symposia. These symposia are scheduled for 2009 in Patras, Greece; 2011 in Edinburgh, Scotland, and 2013 in Berlin, Germany.

The 10th International Symposium on Myelodysplastic Syndromes
Patras, Greece
May 6-10, 2009
President: Nicholas C. Zoumbas
Sponsored by The Myelodysplastic Syndromes Foundation
www.mds2009.org

Tenth International Symposium:
Spring 2009
Patras, Greece
Sponsor: Nicholas C. Zoumbos, MD

Eleventh International Symposium:
Spring 2011
Edinburgh, Scotland
Sponsor: David T. Bowen, MD

Twelfth International Symposium:
Spring 2013
Berlin, Germany
Sponsor: Wolf-Karsten Hofmann, MD, PhD

CALL FOR ABSTRACTS:
DEADLINE
30 JANUARY 2009

Upcoming: Preliminary program including information on abstract submission, registration, accommodation, and excursions will be available on March 15, 2008 at www.mds2009.org and www.epsiloncongress.gr

Local Organizing Secretariat:
EPSILON
4 Papadiamantopoulou Str.
115 28 Athens, Greece
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www.epsiloncongress.gr

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mds2009@epsiloncongress.gr

www.mds2009.org
Patient Information

Medical Glossary of Terms Relating to MDS

Written for Patients

Sometimes it seems that you have to learn a completely new language to understand what your physicians and nurses are telling you about MDS.

We hope that this list of commonly used medical terms and definitions will help you and your family or support person(s) to understand what these terms mean and help you understand MDS.

GENERAL

Acute: A sudden onset of symptoms or diseases.

Acute myeloid leukemia (AML): A cancer characterized by the rapid proliferation of abnormal cells which accumulate in the bone marrow and interfere with the production of abnormal blood cells. AML is the most common acute leukemia affecting adults, and its incidence increases with age, however it can also occur in children. The symptoms of AML are caused by replacement of normal bone marrow with leukemic cells, resulting in a drop in red blood cells, platelets, and normal white blood cells.

Anemia: A condition in which the number of red blood cells is below normal, resulting in fatigue or weakness.

Antibiotics: Drugs used to stop or slow down the growth of germs.

Antibodies: Proteins that help protect the body against foreign substances.

Apheresis: A procedure in which blood is taken from a donor, a blood component (such as white blood cells, red blood cells, or plasma) is separated out, and the remaining blood components are put back into the donor.

Apoptosis: The self-destruction, or suicide, of cells including cancer cells.

Blast cells: Immature blood cells that normally become fully functional mature red cells, white cells, or platelets.

Blood tests: Blood samples drawn from the arm that are evaluated for cell counts (red cells, white cells (and their subtypes), and platelets. The blood is also evaluated for the shape and size of the red and white blood cells and the level of erythropoietin in the serum.

Bone marrow: The soft, sponge-like tissue in the center of bones that functions like a factory to produce white blood cells, red blood cells, and platelets.

Bone marrow aspirate: A sample of the liquid portion of the bone marrow.

Bone marrow aspiration: The process of removing bone marrow from a specific area using a small needle and syringe. Used for making a diagnosis.

Bone marrow biopsy: A sample of the boney portion of the bone marrow.

Chemotherapy: Treatment of a disease with chemical drug agents.

Chromosomes: A structure that contains your genetic information, or DNA. Normally each person has 23 pairs of chromosomes.

Chronic Myelomonocytic Leukemia (CMML): A slowly progressing type of myelodysplastic/myeloproliferative disease in which too many myelomonocytes (a type of white blood cell) are in the bone marrow, crowding out other normal blood cells, such as other white blood cells, red blood cells and platelets.

Clinical trial: A research study designed to evaluate new methods of screening, prevention, diagnosis, or treatment of disease.

Combination chemotherapy: The use of more than one drug during cancer treatments.

Cytogenetics: Testing that is performed on bone marrow samples and examines the chromosomes of the cells. The test gives information about the type of MDS that is present. Common abnormalities include:

1. Deletion 5q—deletion of chromosome 5
2. Deletion 20—deletion of chromosome 20
3. Deletion Y—deletion of Y chromosome
4. Monosomy 7—loss of one of the two 7 chromosomes
5. Trisomy 8—addition of a third chromosome 8

Cytopenia: A deficiency of (or too few) mature cells in the blood. Deficiencies can occur in red cells, white cells, and/or platelets.

Differentiation: The process of cells maturing to become healthy adult cells of a particular type (i.e. red cells, white cells, and platelets).

Dysplasia: Abnormal shape and appearance, or morphology, of a cell.

Erythropoietin: A protein substance manufactured by the kidneys in response to low oxygen levels in body tissues. Erythropoietin stimulates the production of red blood cells in the bone marrow.

FAB Classification: The classification of MDS by the French-American-British (FAB) group. (See page 9 of the MDS Foundation’s Patient Handbook Understanding Myelodysplastic Syndromes)

Fatigue: A feeling of low or no energy, general feeling of tiredness with normal activity.

Ferritin (Serum) or ferritin level: The major iron storage protein found in the intestinal mucosa (lining), spleen, and liver. The blood level of ferritin serves as an indicator of the amount of iron stored in the body. It is expressed as ng/mL or nanograms of iron per milliliter of blood. Normal range of serum ferritin is 20 ng/mL to 300 ng/mL in men and 12 ng/mL to 150 ng/mL in women.

Hematocrit: Percent of the total blood volume that is made up of red blood cells. In men a normal hematocrit is 40—52% while in women the normal is 36—46%. (See red blood cells)

Hematologist: A doctor who specializes in the diseases and disorders of blood.
**Hematopoiesis:** The formation and development of blood cells in the bone marrow.

**Immature blood cells:** May be called stem cells, progenitor cells or blasts.

**Immune system:** The complex group of organs and cells that defends the body against infection and disease.

**Immunosuppressive drug:** Drug given to suppress a patient’s immune system, such as one given to prevent rejection of transplanted tissue.

**IPSS:** International Prognostic Scoring System—system for grading the severity of MDS. (See page 11 of the MDS Foundation’s Patient Handbook Understanding Myelodysplastic Syndromes)

**Iron Overload:** Too much iron in the body which can then build up in the organs and cause disease. It is a particular risk in people with certain genetic disorders such as hemochromatosis and people receiving repeated blood transfusions.

**Myelo:** A Greek word meaning marrow.

**Myelodysplastic syndromes:** A group of diverse bone marrow disorders in which the bone marrow does not produce enough healthy blood cells.

**Neutropenia:** A deficiency (below-normal number) of mature white blood cells (neutrophils).

**Packed RBCs:** A concentrated blood product in which most of the plasma, the fluid part of blood, is removed to make red blood cell transfusions easier and faster.

**Pediatric MDS:** MDS is rare in children; but they do happen. Most patients are 60 years old or older.

**Peripheral blood stem cell (PBSC):** Stem cells collected from the blood. The term “peripheral” means that the cells come from outside the bone marrow.

**Platelets:** Irregularly shaped, colorless cells that are present in blood. Their sticky surface lets them, along with other substances, form clots to stop bleeding. Also called thrombocytes. Stated as Platelets/µL of blood. Normal range 150,000–450,000.

**Remission:** Disappearance of the signs and symptoms of cancer. A remission may be complete (CR) or partial (PR).

**Serum erythropoietin:** Amount of erythropoietin that is present normally in an individual’s blood.

**Stem cells:** Cells that are produced in the bone marrow and develop into either red blood cells, white blood cells, or platelets.

**Thrombocytopenia:** A condition in which the number of mature platelets, or thrombocytes, is below normal, resulting in the tendency to bruise and bleed more easily.

**Transfusion:** Process by which blood or one of its components is delivered directly into the bloodstream.

**White blood cells:** Cells produced in the bone marrow and lymph nodes. White cells are key cells in the immune system that prevent or fight infection. Normally stated in cells/µL. Normal range is 3,200–10,000.

**World Health Organization (WHO) Classification:** Expanded categories of MDS based on the FAB Classification System. (See page 9 of the MDS Foundation’s Patient Handbook Understanding Myelodysplastic Syndromes)

**RED BLOOD CELLS**

**Erythrocyte:** A red blood cell. It carries oxygen to body cells and carbon dioxide away from the cells. (See red blood cells)

**Red blood cells:** Cells, in the blood, that carry oxygen to your tissues.

**WHITE BLOOD CELLS**

**ANC (absolute neutrophil count):** A measure of the actual number of mature neutrophils in a given volume of blood.

**Basophil:** Type of white blood cell that plays a role in allergic reactions.

**Eosinophil:** Type of white blood cell that kills parasites as well as playing a role in allergic reactions.

**Granulocyte:** A term for any of the white blood cell types that have granules containing enzymes to help fight infection: neutrophils, eosinophils and basophils.

**Lymphocytes:** Small white blood cells produced in the lymphoid organs (the lymph nodes, spleen, thymus, and tonsils) that are essential for normal function of the immune system.

**Monocyte:** A white blood cell that helps the body fight infections from bacteria and viruses. (See white blood cells)

**Neutrophil:** A type of white blood cell that functions to destroy bacteria.

**BONE MARROW BIOPSY**

**Biopsy:** The removal and examination of a small piece of tissue from the body to determine a precise diagnosis.

**Iliac crest:** The hip bone area from which bone marrow samples are most commonly taken.

**BONE MARROW TRANSPLANT**

**Allogeneic stem cell transplantation:** A procedure in which bone marrow or peripheral blood stem cells from a donor (usually related) are collected, stored, and infused into a patient (recipient) following high-dose chemotherapy or radiation therapy.

**Allograft:** An allogeneic stem cell transplant.

**Autograft:** An autologous stem cell transplant.

**Autologous stem cell transplantation:** A procedure in which a patient’s own stem cells from bone marrow or peripheral blood are collected, stored, and reinfused following high-dose chemotherapy or radiation therapy.

**Bone marrow transplant:** A procedure in which a patient’s bone marrow is destroyed by high doses of chemotherapy or radiation therapy to eradicate disease and then replaced with healthy bone marrow from a donor or the patient himself.

**Engraftment:** The process by which stem cells in transplanted bone marrow or blood migrate to the recipient’s bone marrow and begin to grow and produce new white blood cells, red blood cells, and platelets.
Graft-versus-host disease (GVHD): Complication of allogeneic transplant resulting from donor leukocytes recognizing the recipient’s cells as foreign and mounting an attack against them.

Mini-allograft: Type of allogeneic stem cell transplant that uses lower doses of chemotherapy or radiation and thus does not completely destroy the bone marrow; also known as mini-transplant or non-myeloablative transplant.

Non-myeloablative transplant: See mini-allograft.

DRUG TREATMENT

Antibiotic therapy: Used to treat bacterial infections or prevent recurrence of bacterial infections.

Antithymocyte globulin (ATG): Is an immunsuppressive agent that eliminates abnormally proliferating white blood cells called T lymphocytes which disrupt normal blood cell growth. This may restore normal red blood cell maturation which may lead to transfusion independence. The three brand-name drugs are Thymoglobulin®, Lymgobulin®, and Atgam®.

Colony-stimulating factor (CSF): Protein that stimulates the development and growth of blood cells; sometimes called growth factor. Granulocyte colony-stimulating factor is a CSF that is used to mobilize stem cells from the bone marrow into the bloodstream prior to apheresis.

Corticosteroids: Also called “steroids,” corticosteroids are powerful anti-inflammatory agents used to treat many diseases and conditions. They are similar to a protein called cortisol that is made in the adrenal glands. Some corticosteroids that you may have heard of are prednisone and dexamethasone.

Dacogen™ (decitabine): Works by preventing certain genes involved in controlling cancer from being silenced, allowing for the normal functioning of the tumor suppressor genes. It is a DNA hypomethylating agent that is administered intravenously (IV), directly into the vein.

Desferal® (deferoxamine): It binds to iron and promotes its removal from the body for treatment of transfusion-dependent iron overload. It is an iron-chelating drug that is administered subcutaneously, into the deeper layer of the skin.

Erythropoietin (EPO): Is a “recombinant” form of a natural growth factor used to treat symptoms associated with anemia. It stimulates the bone marrow to produce red blood cells. The three brand-name drugs are Aranesp®, EpoGen®, and Procrit®. These drugs are administered intravenously, directly into the vein, or subcutaneously, into the deeper layer of the skin.

Exjade® (deferasirox): It binds to iron and promotes its removal from the body for treatment of transfusion-dependent iron overload. It is an iron-chelating drug that is administered orally (by mouth).

Growth factors (hematopoietic): Substances that stimulate blood cells to grow. G-CSF and GM-CSF are two of these factors.

Hycamtin® (topotecan hydrochloride): Is a chemotherapy agent that may result in remission of MDS. It is administered intravenously, directly into the vein.

Leukine® (sargramostim): Is a granulocyte macrophage colony-stimulating factor (GM-CSF) used for the treatment of neutropenia. It increases white cell production, which may help to reduce the likelihood of additional infection. It is administered subcutaneously, into the deeper layer of the skin.

Pyridoxine (Vitamin B6): Can relieve sideroblastic anemia through increases in red cell counts. Patients can take 100 mg of vitamin B6 twice a day orally (by mouth).

Revlimid® (lenalidomide): Works by stimulating the immune system, inhibiting new blood vessel growth, and causing cell death. It is categorized as an immuno-modulatory agent and is administered orally (by mouth).

Telintra™ (TLK199): Stops a key enzyme (glutathione S-transferase P1-1 or GST P1-1) involved in cell growth and division, thereby promoting normal growth and development of all blood cell types. It is administered intravenously, directly into the vein.

Thalomid® (thalidomide): Reduces the blood supply in the marrow, thereby working to limit the growth and spread of abnormal cells. It also acts to thwart cytokines that promote premature death of progenitor cells in the bone marrow. It is administered orally (by mouth).

Trisenox® (arsenic trioxide): Inhibits new blood vessel growth and stimulates cell death. May increase transfusion independence. It is administered as an intravenous infusion, directly into the vein.

Vidaza™ (azacytidine): Works by preventing a cellular process (methylation) that silences the genes involved in controlling the development of cancer. It increases red blood cells, transfusion independence, hemoglobin, white blood cells, platelets, and/or decreases bone marrow blast percentage. It is categorized as a DNA hypomethylating agent and can be administered intravenously, directly into the vein, or subcutaneously, into the deeper layer of the skin.

Practice and Treatment Survey

The Myelodysplastic Syndromes Foundation would like to know more about your approach to the diagnosis and treatment of patients with MDS. Please assist us by completing a brief online survey.

Go to www.mds-foundation.org and click on Practice & Treatment Survey.
Patient and Family Forum Held in Florence, Italy

May 19, 2007

The conference was free of charge and open to all patients with myelodysplasia and their families or guests. Attendees were given an opportunity to actively participate and to share their thoughts concerning problems and lifestyle changes related to living with MDS. Doctors involved in MDS research provided information on MDS and new treatment options. In addition, participants had the opportunity to meet other patients allowing everyone the opportunity to share their stories and concerns.

We would like to thank the faculty as this program generated excellent audience interest and attendance.

PROGRAM

- Living with Myelodysplasia: The Quality-of-Life Problem
  Kathy Heptinstall, Operating Director, The MDS Foundation
- Epidemiology
  Professor Sante Tura
- Support Therapy
  Professor Rossi Ferrini
- Available Therapies and Future Options
  Professors Mario Cazzola and Valeria Santini
- Staminal Cell Transplantation in Myelodysplasia
  Professor Alberto Bosi

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Mayo Clinic Researcher Presents Minnesota Patient Forum

Dr. David Steensma, Mayo Clinic

Rochester, Minnesota

On June 28, 2007, MDS patients and their families had the opportunity to hear a presentation from Dr. David Steensma, a leading MDS researcher, from Mayo Clinic in Rochester, Minnesota. Dr. Steensma did a wonderful job presenting information regarding new therapies, and the latest in medical research. He indicated that new research has greatly enhanced understanding of pathophysiology of MDS and new treatment modalities have been developed. Attendees were also able to ask him questions and have their particular concerns addressed. These Forums are being used to develop educational information for physicians focused on the issues that are most important to patients living with MDS and helpful information for patients living with this disease. Patients and their guests exchanged information and made friends. These patient forums have been very well received by both the physicians, patients and their caregivers.

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Funding has been obtained to support these ongoing meetings and we are actively recruiting patients to facilitate and participate in these groups. Patients, family members, and caregivers are invited to join. If you are interested in joining an existing group or starting a new group in your area, please contact:

Audrey Hassan
Patient Liaison, MDS Foundation
patientliaison@mds-foundation.org
or call 1-800-MDS-0839.

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MGI Pharma has provided the MDS Foundation with an educational grant to support the Foundation’s work.
The Foundation would like to invite patients and their families to share their stories with others in the MDS community. Living with MDS poses challenges and many of you have stories that provide hope to others.

Please contact the Foundation, if you would like us to publish your story!!!

My Story...

Bill Stroup
Jacksonville, Florida

My name is Bill Stroup, a 70-year old retired university chaplain living in Jacksonville, Florida. A 10-year prostate cancer survivor with recent bone metastases, I did not respond well to chemotherapy (my WBC dropped to 550 and my temp rose to 104˚+ after only two treatments), so my oncologist and I chose to treat the spinal metastases with radiation.

Two months following my 51st radiation treatment over that 10 year period, my hematology results began sliding lower on each weekly visit. On May 15, 2007, bone marrow aspiration/biopsy results revealed MDS. It’s amazing how my entire family’s focus moved from the symptoms and treatment of metastatic cancer to the understanding and management of this new diagnosis. We had never even heard the term. It was almost as if the “cancer” no longer mattered: myelodysplasia and all of its ramifications took center stage.

Being an optimistic man with strong religious faith, I sought to amend my layman’s comprehension of clinical reports through a linguistic hobby, original word study: I decided to look up the meaning of myelodysplastic syndrome in my Greek lexicon and to also see where these terms appeared in the New Testament writings of the Bible. Not only has this exercise broadened my understanding of what’s going on in my body, it has enabled my family and friends to develop an enlightened overview of MDS and it has kept them from volunteering an unending list of well-meaning but ineffective therapies.

Myelo is the Greek word for “bone marrow.” Plasia is both a verb for “forming” and a noun for “something formed.” Syndrome comes from a term meaning “run together.” The Dys is a prefix that turns any word into its negative opposite. The Biblical references have nothing to do with MDS specifically, but give perspective to our current usage. The Word of God is said to be sharper than a two-edged sword in its ability to divide between joints and marrow; the term plasia appears with reference to Adam who was formed before Eve; and syndrome is used to describe how lots of people ran together flocking around Jesus or his disciples whenever a miracle was performed. It’s the prefix, dys, that identifies the pathological nature of MDS. The marrow which is supposed to form good blood cells from stem cells not only fails to do so in required quantities and quality, it is so compromised in its manufacturing function that it systematically mis-forms whatever cells are generated. These inferior cells either die in the marrow or shortly after entering the blood stream, cluttering it up with “blasts.” The net result? the entire body joins in as each organ and function irrevocably declines. Chemical signals calling for more production literally and figuratively “fall on deaf ears.”

I have begun a few blood transfusions but the positive results are meager and short-lived. Hospice services have been engaged and I am encouraged daily by these word studies, contact with friends and my faith. Thanks for the contributions of the MDS Foundation.

Join the Journey to Hope Bracelets

In loving memory of her mother and sister who passed away from MDS, Sandy Madrigal has created handcrafted bracelets dedicated to promoting awareness to MDS.

Each bracelet is made with a combination of Swarovski crystals, with fine Japanese glass beads, antique Rhodium (a lead-free pewter), silver plated and sterling silver accents.

Give a Gift of Hope...
10% of the sale of each bracelet will be donated to the MDS Foundation

To order for only $20.00, please visit www.lovinkissesbeading.com and email sandy@lovinkissesbeading.com or call 800-MDS-0839.

A $2.00 shipping and handling fee will be applied to each order. International orders may have additional shipping costs.
Drug News

Vidaza Significantly Extends Overall Survival by 74% in Phase 3 Trial in Myelodysplastic Syndromes (MDS)

- Two year survival rate of 50.8 percent for Vidaza versus 26.2 for conventional care regimens
- 9.4 months median survival benefit for patients on Vidaza compared to conventional care regimens
- Only agent to demonstrate survival benefit in MDS compared to conventional care regimens
- Only epigenetic modifier to show survival benefit in cancer
- Stratified log-rank P-value = 0.0001, Hazard ratio = 0.58
- Largest study ever conducted in higher-risk MDS

On August 2, 2007, Pharmion Corporation announced in their press release topline results from the multi-institutional, international, randomized, Phase 3 controlled trial of Vidaza® (azacitidine for injection) versus conventional care regimens (CCR) in the treatment of patients with higher-risk myelodysplastic syndromes (MDS). In the primary endpoint analysis, Vidaza treatment was associated with a median survival of 24.4 months versus 15 months for those receiving CCR treatment, an improvement of 9.4 months with a stratified log-rank P-value of 0.0001. The hazard ratio describing this treatment effect was 0.58 (95 percent confidence interval of 0.43 to 0.77). Two-year survival rates were 50.8 percent versus 26.2 percent for patients receiving Vidaza versus CCR (P < 0.0001). Median number of treatment cycles was nine for Vidaza.

The survival benefits of Vidaza were consistent regardless of the CCR treatment option (best supportive care (BSC) alone, low-dose cytarabine plus BSC or standard chemotherapy plus BSC) utilized in the control arm.

“These landmark results, showing a significant improvement in survival in the most advanced MDS patients, validate the benefit Vidaza can provide patients with this extremely difficult to treat disease,” said Dr. Lewis R. Silverman, Associate Professor of Medicine, Division of Hematology and Medical Oncology, Mount Sinai School of Medicine. “Building on the established data from our earlier clinical studies, which showed that Vidaza offers transfusion independence to many patients with MDS, we now see that Vidaza not only improves a patient’s life, but extends it as well.”

“With these very exciting results for Vidaza, survival should now be the standard by which we evaluate treatment options for higher-risk MDS,” said Dr. Alan F. List, Chief, Malignant Hematology Division and Deputy Physician in Chief, H. Lee Moffitt Cancer Center and Research Institute. “Importantly, as the first and only epigenetic therapy to have demonstrated a survival benefit in any cancer, these findings should accelerate exploration of Vidaza in other malignancies where hypermethylation is believed to play a key role in tumor development and progression.”

“We are extremely gratified with the results from the Vidaza Survival Study, which for the first time bring the hope of prolonged survival for patients with higher-risk MDS,” said Patrick J. Mahaffy, Pharmion’s chief executive officer and president. “As the only therapy to have ever demonstrated a survival advantage in MDS, and especially to have demonstrated an improvement of this magnitude, Vidaza is unique in the treatment for this disease.”

Pharmion plans to present full study results at an upcoming medical meeting. Based on these results, Pharmion intends to file a Marketing Authorization Application (MAA) in the European Union (EU) for Vidaza for the treatment of higher-risk MDS before the end of this year and will shortly thereafter submit additional international regulatory submissions. The Company will also file a supplemental New Drug Application (NDA) with the U.S. Food and Drug Administration (FDA) to include these data in the prescribing information in the U.S.

Pharmion is also developing a next generation product, oral Azacitidine, for the treatment of MDS and other cancers where demethylation can provide an anti-tumor effect. Oral Azacitidine is the subject of a Phase 1 multi-center, open label dose escalation trial that will assess the maximum tolerated dose, dose limiting toxicities and safety of a seven day, multi-cycle oral dosing regimen of oral Azacitidine in patients with MDS and AML. In addition, the trial will examine pharmacokinetics and pharmacodynamic effects of orally administered Azacitidine, as compared with parenteral Vidaza.

Purchase MDS Awareness Pins

The MDS Foundation has enameled lapel pins for you to wear with pride and to increase public awareness about MDS. The pins are available with a $3.99 donation to The MDS Foundation. To order your pins, call The MDS Foundation at 1-800-MDS-0839.

This item was created especially for The MDS Foundation to contribute to the effort to help people worldwide living with myelodysplastic syndromes. Your donation will help increase awareness of this little known disease, which is the most common of the hematologic malignancies. Please ask your family and friends to wear these pins in support of our mission!
CMS Decision on Proposed Removal of Aranesp, Epogen, and Procrit from Medicare Reimbursement

The Centers for Medicare and Medicaid Services (CMS) has retreated from its initial position of denying patients suffering from myelodysplastic syndromes (MDS) coverage for erythropoietin stimulating agents (ESAs).

The response from both the medical and MDS patient communities was overwhelmingly critical of the proposed reimbursement changes that would have denied coverage to MDS patients being treated with ESAs (Epogen, Aranesp, Procrit), the majority of whom are over the age of 65.

The MDS Foundation addressed this issue from many different aspects including submission of key scientific documentation regarding the use of ESAs in MDS to CMS, alerts to patients regarding the need for MDS patients, their families, and friends to respond to CMS directly (which they did in record numbers), testimony and consultations offered to CMS from physicians and researchers working in the field of MDS, testimony before the Oncology Drug Advisory Committee of the FDA by Steven Gore, MD of Johns Hopkins University, and direct correspondence and personal discussion with members of key Congressional and Senate Committees.

CMS made no recommendation regarding the coverage of ESAs for MDS. This means that local Medicare contractors will make individual decisions regarding coverage for ESAs for MDS patients.

An MDS patient and a Member of the Foundation’s Board of Directors, Robert Weinberg said that, “From the standpoint of the MDS patient community, we welcome recognition by our congressional representatives of the important role played by erythropoiesis-stimulating agents in the treatment of anemia caused by MDS. We will be relieved when all threats are removed to the availability of these agents for MDS patients.”

Even though the public comment period for CMS has ended, it is still important for you to contact your U.S. Representative! Members of Congress do not support these types of resolutions unless they hear from their constituents. Tell them this is unfair to MDS patients in the United States. Spread the word and contact your elected Representative today!

Please continue to monitor our website, www.MDS-Foundation.org for information regarding this issue and others of importance to MDS patients worldwide. If we can assist you in any way (including information on the use of ESAs in MDS) please do not hesitate to contact us via e-mail at: patientliaison@mds-foundation.org or by phone at 800-MDS-0839.

Be a Bone Marrow Donor

For those patients diagnosed with a fatal blood disorder, bone marrow transplantation (BMT) is often the only chance of survival. Related donors provide suitable matches only 33 percent of the time. This leaves nearly 70 percent of patients without a match. The need is especially critical in racial and ethnic minority groups.

Registering as a donor is simple. A blood sample is all you need to enter your tissue type into the National Marrow Donor Program (NMDP) computerized registry. If you are in good health and between the ages of 18 and 55, you can contact NMDP at 1-800-MARROW-2. They will send additional information, including the NMDP center nearest you. Give the Gift of Life!

Other sites of interest:

ASBMT™ American Society for Blood and Marrow Transplantation: www.asbmt.org

International Bone Marrow Transplant Registry: www.isbmt.org

National Marrow Donor Program®: www.marrow.org

Blood & Marrow Transplant Information Network: www.bmtinfonet.org

Blood & Marrow Transplant Resources: www.BMTresources.org

Over 140 Things You Need to Know about Your Autologous Bone Marrow or Stem Cell Transplant is available online at www.BMTresources.org or call (414) 870-4850, ISBN# 0-9768060-0-2/Price: $11.95. Contains over 140 invaluable tips to help transplant patients sail through their procedures.
# MDS Patient Registry

The patient registry form has been revised and a patient authorization form has been developed to meet HIPAA guidelines. The Patient Registry will help further research into the etiology, diagnosis and treatment of MDS. Currently, the MDS Patient Registry is only accepting patients through our designated Centers of Excellence. A two page data sheet will be forwarded to investigators who wish to contribute patient’s names to the Registry. The Registry is located at the MDS Foundation’s Statistical Center at the University of Rochester Cancer Center.

The Foundation looks forward to building the Patient Registry with our Centers of Excellence.

If you would like to become a Center of Excellence, please contact The Foundation at the address below.

The MDS Foundation, Inc.
36 Front Street, P.O. Box 353
Crosswicks, NJ 08515
Phone: 1-800-MDS-0839 within the US
Outside the US only: 1-609-298-6746
Fax: 1-609-298-0590.

# Slone Patient Registry

The Slone Epidemiology Center at Boston University is enrolling patients who have recently been diagnosed with myelodysplastic syndromes in a voluntary research project called the Patient Registries at Slone: MDS. The registry gathers important information about the impact of MDS and its treatments on patients’ physical, emotional, social, and economic well-being. Participation in the Registry does not affect the care or treatments that patients receive.

You are eligible to join if:
- You have been diagnosed with MDS within the past 3 months
- You live in the US

You do not need to have received any medicines or other treatments for your MDS to be eligible.

For more information or to enroll:
Visit [http://www.bu.edu/prs/mds](http://www.bu.edu/prs/mds), e-mail mdsinfo@slone.bu.edu or call the registry at 800-231-3769.

# Patient Referrals

Myelodysplastic syndromes can be difficult to diagnose and treat. It is important for both patients and their families to know that optimal treatment is available and that quality-of-life can be enhanced.

If you would like information about treatment options, research, or quality-of-life, we would be glad to help. The Foundation offers a variety of patient services, including preferential referrals to the Foundation’s MDS Centers of Excellence. We can also help identify physicians and centers to support you if you are travelling and need assistance.

Please contact us at:
1-800-MDS-0839 (phone)
or 609-298-0590 (fax).
Outside the US please call: 609-298-1035.
You can visit our website at: [http://www.mds-foundation.org](http://www.mds-foundation.org).

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## ICD9 Coding Changes

Changes have been made to the ICD codes for MDS. The following sequence reflects the WHO plus the now extinct but still classifiable RAEB-T:

<table>
<thead>
<tr>
<th>Diagnostic Term</th>
<th>ICD-0-3</th>
<th>ICD-9-CM</th>
</tr>
</thead>
<tbody>
<tr>
<td>Refractory Anemia</td>
<td>C42.1</td>
<td>M-9980/3</td>
</tr>
<tr>
<td>Refractory Anemia with Ringed Sideroblasts</td>
<td>C42.1</td>
<td>M-9982/3</td>
</tr>
<tr>
<td>Refractory Anemia with Excess Blasts</td>
<td>C42.1</td>
<td>M-9983/3</td>
</tr>
<tr>
<td>Refractory Anemia with Excess Blasts in Transformation</td>
<td>C42.1</td>
<td>M-9984/3</td>
</tr>
<tr>
<td>Refractory Cytopenia with Multilineage Dysplasia</td>
<td>C42.1</td>
<td>M-9985/3</td>
</tr>
<tr>
<td>Myelodysplastic Syndromes (MDS) with 5q-Syndrome</td>
<td>C42.1</td>
<td>M-9986/3</td>
</tr>
<tr>
<td>Therapy-related Myelodysplastic Syndromes (MDS)</td>
<td>C42.1</td>
<td>M-9987/3</td>
</tr>
<tr>
<td>Myelodysplastic Syndromes, NOS</td>
<td>C42.1</td>
<td>M-9989/3</td>
</tr>
</tbody>
</table>
Would you like your treatment center to become part of the referral system for MDS patients and be designated as a Center of Excellence? To be recognized as a Center of Excellence, an institution must have the following:

- An established university (or equivalent) program
- Recognized morphologic expertise in MDS
- Available cytogenetics and/or molecular genetics
- Ongoing research, including Institutional Review
- Board–approved clinical trials
- Documentation of peer-reviewed publications in the field
- The ability and intention to register patients in the MDS International Registry database

Please contact the Foundation for further information and an application form for your center.

The following centers have qualified as MDS Centers of Excellence:

**UNITED STATES**

**ALABAMA**
University of Alabama at Birmingham Comprehensive Cancer Center
Birmingham, Alabama
James M. Foran, MD

**ARIZONA**
Mayo Clinic Hospital
Phoenix, Arizona
James L. Slack, MD
University of Arizona
Arizona Cancer Center
Tucson, Arizona
Daruka Mahadevan, MD, PhD

**CALIFORNIA**
Cedars-Sinai Medical Center
UCLA School of Medicine
Los Angeles, California
H. Phillip Koeffler, MD
City of Hope National Medical Center
Duarte, California
Stephen J. Forman, MD
Stanford University Medical Center
Stanford, California
Peter L. Greenberg, MD
UCLA Center for Health Science
UCLA School of Medicine
Los Angeles, California
Gary J. Schiller, MD
University of Southern California
Keck School of Medicine
Los Angeles, California
Allen S. Yang, MD, PhD

**FLORIDA**
Mayo Clinic
Jacksonville, Florida
Alvaro Moreno-Aspilta, MD
University of South Florida, H. Lee Moffitt Cancer Center and Research Institute
Tampa, Florida
Alan F. List, MD

**ILLINOIS**
Loyola University Chicago
Cardinal Bernardin Cancer Center
Maywood, Illinois
Scott E. Smith, MD, PhD
Robert H. Lurie Comprehensive Cancer Center of Northwestern University Feinberg School of Medicine
Chicago, Illinois
Olga Frankart, MD
Rush University Medical Center
Chicago, Illinois
Stephanie A. Gregory, MD/Lamie Shamma, MD
University of Chicago Medical Center
Chicago, Illinois
Richard A. Larson, MD

**INDIANA**
Indiana University Medical Center
Indianapolis, Indiana
Larry Cripe, MD

**MARYLAND**
Johns Hopkins University School of Medicine
Baltimore, Maryland
Steven D. Gore, MD/Charles S. Hesdorffer, MD
National Heart, Lung, and Blood Institute
Baltimore, Maryland
Jelena Slobod, MD
University of Maryland Greenebaum Cancer Center
Baltimore, Maryland
Maria R. Baer, MD/Ivana Bojo, MD

**MASSACHUSETTS**
Dana-Farber Cancer Institute
Boston, Massachusetts
Richard M. Stone, MD
Tufts University School of Medicine
New England Medical Center
Boston, Massachusetts
Kefie Traugule, MD

**MICHIGAN**
Barbara Ann Karmanos Cancer Institute
Wayne State University
Detroit, Michigan
Charles A. Schiffer, MD
William Beaumont Hospital Cancer Center
Royal Oak, Michigan
Ishmael Jaiyesimi, MD

**MINNESOTA**
Mayo Clinic
Rochester, Minnesota
David P. Steensma, MD

**MISSOURI**
Washington University School of Medicine
Siteman Cancer Center
St. Louis, Missouri
John F. DiPersio, MD, PhD

**NEBRASKA**
University of Nebraska Medical Center
Omaha, Nebraska
Lori Mones, MD

**NEW JERSEY**
The Cancer Center of Hackensack University Medical Center
Hackensack New Jersey
Stuart Goldberg, MD

**NEW MEXICO**
University of New Mexico Health Sciences Center
Albuquerque, New Mexico
Robert Hromas, MD

**NEW YORK**
Albert Einstein College of Medicine Cancer Center
Bronx, New York
Andr Verma, MD
Memorial Sloan-Kettering Cancer Center
New York, New York
Stephen D. Nimer, MD
Mount Sinai School of Medicine
New York, New York
Lewis R. Silverman, MD
New York Medical College/Westchester Medical Center
Valhalla, New York
Karen Selit, MD
North Shore University Hospital
Lake Success, New York
Steven L. Allen, MD
Roswell Park Cancer Center
Buffalo, New York
Minoo Battaevale, MD
St. Vincent’s Comprehensive Cancer Center
New York, New York
Aza Rana, MD
University of Rochester Cancer Center
Rochester, New York
John M. Bennett, MD
Weill Medical College of Cornell University
New York Presbyterian Hospital
New York, New York
Eric J. Feldman, MD

**NORTH CAROLINA**
Duke University Medical Center
Durham, North Carolina
Carlos M. deCastro, MD
Wake Forest University School of Medicine Comprehensive Cancer Center
Winston-Salem, North Carolina
Jen Mar, MD

**OHIO**
Cleveland Clinic Foundation Tausig Cancer Center
Cleveland, Ohio
Jaroslav Maciejewski, MD, PhD

**OREGON**
Oregon Cancer Center at Oregon Health and Science University
Portland, Oregon

**PENNSYLVANIA**
The Western Pennsylvania Cancer Institute
University of Pittsburgh Cancer Institute
Pittsburgh, Pennsylvania
Anastasios Raptis, MD

**TENNESSEE**
St. Jude Children’s Research Hospital
Memphis, Tennessee
Gregory Hale, MD

**TEXAS**
Southwest Regional Cancer Center
Austin, Texas
Richard Helmer, III, MD
University of Texas MD Anderson Cancer Center
Houston, Texas
Elhu H. Easley, MD
University of Texas Southwestern Medical Center
Dallas VA Medical Center
Dallas, Texas

**WASHINGTON**
Fred Hutchinson Cancer Research Center
Seattle, Washington
Joachim Deeg, MD
Seattle Cancer Care Alliance
University of Washington
Seattle, Washington
John A. Thompson, MD

**WISCONSIN**
Medical College of Wisconsin
Bone Marrow Transplant Program
Milwaukee, Wisconsin
Elise Pawar, MD
University of Wisconsin
Madison Medical School
Madison, Wisconsin
Mark B. Juckett, MD

**OUTSIDE THE UNITED STATES**

**AUSTRALIA**
Peter MacCallum Cancer Institute
University of Melbourne
East Melbourne, Australia
John F. Seymour, MD
University of Tasmania
Royal Hobart Hospital
Hobart, Tasmania, Australia
Raymond M. Lowenthal, MD
International Clinical Trials: An Update

NATIONAL CANCER INSTITUTE TRIALS

As we go to press the National Cancer Institute (NCI) has listed more than 100 clinical trials that focus on Myelodysplastic syndromes. Full study information on these trials is available at www.nci.nih.gov. This information includes basic study information, study lead organizations, study sites, and contact information. To access the information:

- Log on to www.nci.nih.gov
- Click on “Finding Clinical Trials”
- On the next screen look for “Ways to Find Clinical Trials” and
- Click on “Search for Clinical Trials”
- Click on “Type of Cancer” and type in ‘myelodysplastic syndromes’
- Hit search

This search will provide you with all the trials currently underway in MDS. You may also sort by trials that only focus on treatment or trials that only focus on supportive care.

To view listings of additional studies you can log onto www.clinicaltrials.gov. You can also contact 1-800-4-CANCER for more information.

If you are an MDS patient, you may wish to discuss a trial with your primary treating physician to see if you qualify as a candidate.

Clinical trials study new interventions (drugs or procedures) to evaluate their safety and effectiveness in humans. Trials follow a careful set of steps, allowing for the systematic gathering of information to answer questions and confirm hypotheses that were formed earlier, in either laboratory experiments or preliminary trials.

A clinical trial falls into one of four phases:

**Phase I.** This is the first time a drug is used in humans. The trial is designed to determine dosage, route of administration (oral, intravenous, or by injection), and schedule of administration (how many times a day or week). In this phase researchers also begin to determine the drug’s safety. The phase I trial is normally conducted in healthy adults and enrolls only a small number of people.

**Phase II.** Patients with the disease receive the drug at dose levels determined in the earlier phase. The phase II trial begins to determine the effectiveness of the drug and provides more information about its safety.

**Phase III.** The drug is tested alone or against an approved standard drug. The typical phase III trial enrolls a large number of patients. If it is a comparison trial, patients may be randomly assigned to receive either the new drug or the standard intervention.

**Phase IV.** In phase IV the drug, already approved by the FDA and available to the public, undergoes continued evaluation. The phase IV designation is rare. Some trials—screening studies evaluating supportive care or prevention—are not conducted in phases. In these trials a group following a certain disease combating strategy, such as a detection method, is compared to a control group.

New Research Protocol Listings

The MDS Foundation wants you to know about clinical trials of investigational treatment options for patients with MDS and has updated its International Clinical Trials list on our website and for distribution.

For a detailed listing featuring new protocols visit http://www.mds-foundation.org, email patientliaison@mds-foundation.org or call 800-MDS-0839 and the current clinical trials will be sent to you under separate cover.

Clinical trials often have very specific eligibility requirements. Please talk with your doctor to help decide which, if any, trials might be right for you.

Please note that the information is provided strictly as a resource and is not an endorsement of any physician, institution or treatment.

Important Research Study Opportunity

Researchers at the H. Lee Moffitt Cancer Center and Research Institute in Tampa, FL are looking for people who have recently been diagnosed with MDS to participate in a research study designed to better understand why people get myelodysplastic syndrome. Specifically, researchers are studying a part of the chromosome called the telomere to see if telomeres are shorter in people with MDS as compared to people who don’t have MDS. A specific gene, called human telomerase reverse transcriptase, or hTERT, will also be studied, to see if hTERT is related to telomere length. People who participate in this study will be asked to complete a questionnaire and provide a blood sample.

Participation in this research study will not in any way affect an individual’s medical care or MDS treatment options.

To find out more information about this important research study, please contact Kristen Jonathan at 813-745-8395 or email kristen.jonathan@moffitt.org.

Telik has provided the MDS Foundation with an educational grant to support the Foundation’s work.
Clinical Research Trial with Lonafarnib—Now Open for Accrual

A Pivotal Randomized Study of Lonafarnib (SCH66336) versus Placebo in the Treatment of Subjects with Myelodysplastic Syndrome (MDS) or Chronic Myelomonocytic Leukemia (CMML) Who Are Platelet Transfusion Dependent With or Without Anemia (Protocol No. P02978)

Study Background
- Lonafarnib (SCH66336) is a potent, orally bioavailable, specific inhibitor of farnesyl transferase. As a farnesyl transferase inhibitor (FTI), Lonafarnib prevents the farnesylation of specific target proteins, including RAS, which are involved in the regulation of cellular proliferation.
- Preclinical data have demonstrated activity of Lonafarnib against numerous neoplastic cell lines in vitro, including several derived from subjects with myeloid and lymphoid leukemias. Lonafarnib has also inhibited the growth of primary leukemia cells derived from subjects with CMML.
- These data suggest that Lonafarnib may have clinical efficacy against a variety of hematologic malignancies and deserves further study.

Key Eligibility Criteria
- Platelet transfusion-dependent MDS or CMML patients with or without anemia diagnosed with de novo disease as confirmed by bone marrow aspirate

Additional Eligibility Criteria
- Diagnosed MDS as classified by the French-American-British (FAB) classification and defined as refractory anemia (RA), refractory anemia with ringed sideroblasts (RARS), refractory anemia with excess blasts (RAEB), and refractory anemia with excess blasts in transformation (RAEB-T), or chronic myelomonocytic leukemia (CMML).
- No prior therapy with farnesyl transferase inhibitors
- No current therapy with any drugs for the treatment of MDS/CMML other than best supportive care within 12 weeks prior to randomization
- ECOG performance status 0 to 2
- Sexually active women of childbearing age will need to use adequate birth control methods while in the study and will be required to maintain this method throughout the study

Learn More About P02978

The MDS Foundation wants you to know about clinical trials of investigational treatment options for patients with MDS. In the current clinical research trial, all patients will receive therapy with Lonafarnib, an investigational drug that is being evaluated for treating patients with MDS or CMML who have been regularly receiving at least 1 and not more than 8 platelet transfusions every 4 weeks. The medicine is taken by mouth at home, and although patients will be monitored closely, routine hospital stays are not required.

About the MDS Foundation: The MDS Foundation is a publicly supported, multidisciplinary, international organization devoted to the prevention, treatment, and study of MDS. The Foundation has conducted international symposia and has established an international information network that provides patients with referrals to the MDS Foundation’s Centers of Excellence worldwide, contact names for available programs, and information about new research and treatment options. The Foundation also provides educational support to both physicians and patients.

For more information about clinical trials with Lonafarnib, call the MDS Foundation at 1-888-813-1260 (outside the US 609-298-7741). Talk to your doctor to decide if this trial is suitable for you.

Clinical Research Trial For An Oral, At-Home Treatment Option
Lonafarnib Clinical Trial Site List (at date of publication)

UNITED STATES
Alvin and Luis Lapidus Cancer Institute
Baltimore, MD
Stephen Noga, MD

University of Minnesota
Minneapolis, MN
Mark Reding, MD

Georgia Cancer Specialists
Tucker, GA
Mansoor Saleh, MD

New York Presbyterian Hospital
New York, NY
Eric Feldman, MD

New York Medical College
Valhalla, NY
Karen Seiter, MD

Bethesda Research Center
Boynton Beach, FL
Roger Brito, MD

University of Massachusetts Medical Center
Worcester, MA
Azra Raza, MD

University of Texas Southwestern Medical Center
Dallas, TX
Robert Collins, MD

James A. Haley Veterans Hospital
Tampa, FL
Hussain Saba, MD

University of South California, Norris Cancer Center
Los Angeles, CA
Dan Douer, MD

Mayo Clinic Hospital
Phoenix, AZ
James Slack, MD

Scripps Cancer Center
La Jolla, CA
James Mason, MD

CANADA / LATIN AMERICA
Canada

Cross Cancer Institute
Edmonton, Alberta
Robert Turner, MD

Sunnybrook Regional Cancer Center
Toronto, Ontario
Rena Buckstein, MD

Princess Margaret Hospital
Toronto, Ontario
Andre Claudius Schuh, MD

Colombia

Fundacion Santa Fe de Bogota
Bogota, Colombia
Monica Duarte Romero, MD

Instituto de Cancerologica SA
Medellin, Colombia
Andres Karduss, MD

Hospital Militar Central
Bogota, Colombia
Benjamin Ospina, MD

Cardio Diagnostico SA
Barranquilla, Colombia
Miguel Urina, ME

Ecuador

Hospital Carlos Andrade Marin
Quito, Ecuador
Jose Paez, MD

Hospital SOLCA Guayaquil
Guayaquil, Ecuador
Bella Maldonado, MD

Cruz Rojo Ecuatoriana
Quito, Ecuador
Juan Sghirla, MD

El Salvador

Hospital Nacional Rosales
San Salvador, El Salvador
Hector Valencia, MD

Peru

Hospital Nacional Edgardo Rebaglianti
Jesus Maria, Peru
Juan Navarro, MD

Puerto Rico

Doctors Cancer Center
Manati, Puerto Rico
Kenel Fernandez-Barbosa, MD

San Juan Hospital
San Juan, Puerto Rico
Luis Baez-Diaz, MD

San Juan VA Medical Center
San Juan, Puerto Rico
William Caceres, MD

EUROPE

Austria

University Clinic of Vienna
Vienna, Austria
Peter Valent, MD

Hanusch Hospital of Vienna
Vienna, Austria
Thomas Noesslinger, MD
Michael Pfliestoecker, MD

Thank You to Our Pharmaceutical Supporters

We would like to thank our pharmaceutical supporters for their commitment to the Foundation and its work. They have contributed in the form of educational grants, which maintains not only this newsletter but also the development of the MDS homepage on the World Wide Web, the Center of Excellence program, continuing medical education programs, the Patient Registry, and the dissemination of patient information.
The MDS Foundation opens its EU Office!

Sophie Wintrich
European Patient Liaison Officer
The MDS Foundation

I’m delighted to join the MDS Foundation in the capacity of European Patient Liaison Officer. My position is made possible through a grant from the MDS Foundation and additional support from King’s College London.

I was born in France, grew up in Germany, studied languages in Paris and gained an MA as a translator at the University of Surrey in the UK. In 1994, my multi-lingual background (French, German and Italian) led me to work for the international medical market research company Fieldwork International/Synovate Group based in London. I initially worked there as an interviewer, then as a Project Coordinator and finally as Project Manager. I quickly developed a specific and keen interest for patient research work and in 2001 started setting up the Patient Research Department within Fieldwork International. Market research projects that I managed included Breast Cancer, MS, Diabetes, Alzheimer’s Disease, AMD, Hemophilia, MDS, Growth Hormones and often involved cooperation from various patient support groups. My interests include traveling and psychotherapy.

I started working for the MDS Foundation in August 2007 and I’m enjoying every minute of it. If I can be of assistance, please contact me at:

The Rayne Institute, Denmark Hill Campus,
123 Coldharbour Lane, London SE5 9NU, UK,
Tel +44 20 7848 5804
Email: swintrich@mds-foundation.org.

I look forward to supporting the work of the Foundation in Europe, the United Kingdom, and emerging European nations!

MDS White Paper Available Through MDS Foundation

This MDS White Paper discusses comparative data and the potential clinical benefits of treatments that are either approved by the U.S. FDA or the EMEA or are under consideration by these bodies. This paper and a subsequent peer-review manuscript will hopefully assist physicians in matching patients with treatment. Coupled with the Foundation’s other endeavors we hope to impact the care that is available to patients around the world. To download your free pdf copy, visit our website www.mds-foundation.org or, if you prefer, call 800-MDS-0839 to request a hard copy.
The Foundation Resource Center is Now Online!

This educational center is designed to provide clinicians, researchers, and other healthcare professionals with a comprehensive source for the latest information and educational programming on the myelodysplastic syndromes.

In the Conference section of our website you can view materials presented at MDS conferences or register for upcoming MDS-related symposia.

Understanding MDS:
A Primer for Practicing Clinicians

Visit www.mds-foundation.org and click on The MDS Foundation Resource Center to take advantage of this comprehensive program, and other informative programs coming soon, designed to provide you with tools and information that will assist you in administering the best care to your patients.

Written programs are available in Spanish, French, Italian, German and Japanese.

Segment 2:
Clinical Presentation, Diagnosis & Pathology

Segment 2 provides insight into the clinical picture of adult and pediatric MDS, primary and secondary MDS, FAB and WHO Classification system, and rationale for the proposed MDS pediatric classification system.

Segment 3:
Ineffective Hematopoiesis: Considerations in Diagnosis and Treatment

Segment 3 provides insight into the pathogenic mechanisms that contribute to the development of MDS, including the altered bone marrow microenvironment of MDS in terms of cells, cytokines, growth factors, receptors, and microvasculature; dyserythropoiesis in MDS, and therapeutic targets and approved drugs for the treatment of MDS.

Segment 1:
The Past and Present In MDS

Segment 1 provides insight into the history of MDS, development of the MDS classification and prognostic systems, and a glimpse into the future of MDS diagnosis, research and treatment.

Segment 4:
Anemia in MDS: Survival, QoL, and Treatment Options

COMING SOON!

This multi-segment program will allow participants to choose the segments that interest them and to learn at their own pace. Segments may be completed via a written program, on-line in our technologically advanced MDS Foundation Educational Center, or via CD-ROM on their personal computer.

The program is approved for 1 hour of CME credit upon completion. There is no charge for this educational activity.

The Myelodysplastic Syndromes Foundation strives to serve as an effective conduit for information regarding the most updated treatment options, clinical studies, referrals to Centers of Excellence, and other information concerning MDS. Please bookmark our site, www.mds-foundation.org, and check back frequently for new, informative programs.
Help the Foundation and Buy Your MDS Textbooks From Us!

Myelodysplastic Syndromes: Clinical and Biological Advances
Peter L. Greenberg, MD
Stanford University Medical Center
Hardback, Nov. 2005/320 pp., illus.
ISBN: 0521496683/$125.00**
Cambridge University press

As the current major comprehensive reference on all aspects of the clinical classification underlying pathogenetic mechanisms and treatment of the myelodysplastic syndromes, Myelodysplastic Syndromes stands out as the definitive text on the genetics, pathophysiology, and clinical management of this wide range of syndromes. Authored by international experts, this book provides a state-of-the-art update of the current status and recent advances in the field. The chapters cover all aspects of the myelodysplastic syndromes, from an in-depth analysis of the multifactorial nature of this disease, including a careful assessment of stromal, immunological and stem cell abnormalities, to a review of recent molecular and cytogenetic discoveries and insights.

This book will be a valuable resource to clinicians and researchers who wish to learn more about myelodysplastic syndromes.

Myelodysplastic Syndromes & Secondary Acute Myelogenous Leukemia: Directions for the New Millennium (Cancer Treatment and Research)
Edited by:
Azra Raza, MD; Suneel D. Mundle, PhD
June 2001/278 pp., illus.
ISBN: 0792373660/$198.00**
Springer Science+Business Media, Inc.

Myelodysplastic syndromes are to the bone marrow what pneumonia is to the lungs; the response of an organ to a variety of etiologic insults like aging, toxic exposure, infections and auto-immunity. Among infectious causes alone, pneumonia could be the result of a variety of possible pathogens including bacterial, viral, tuberculous or fungal agents. Similarly, MDS cannot be treated as a single disease. Attempts to harness the inherent complexity of MDS by devising “classifications” which group the various syndromes as one disease is as misguided as saying that a pneumonia is not infectious because it did not respond to antibiotics. Progress in the field will occur faster when we re-analyze this premise. Therefore, until a clearer picture of the disease emerges it is best to treat each of the MDS syndromes as a separate entity. Having no classification is better than a misleading one. This book is our attempt to define the most crucial questions related to MDS that need to be addressed immediately through logic, analysis and rigorous experimentation. If the emerging problems appear daunting, then instead of being overwhelmed by them, we should follow the advice of the great 20th century thinker Antonio Gramsci, “pessimism of the intellect must be faced with the optimism of will”.

The Myelodysplastic Syndromes Pathobiology and Clinical Management (Basic and Clinical Oncology Series/27)

Edited by:
John M. Bennett, MD
James P. Wilmot Cancer Center of the University of Rochester, Rochester, New York, U.S.A.

May 2002/528 pp., illus.
ISBN: 0-8247-0782-6/$165.00**
CRC Press. 800-272-7737

This reference provides a comprehensive overview of the latest research detailing the etiology, epidemiology, treatment, and detection of myelodysplastic syndromes (MDS)—identifying effective therapeutic regimes, adverse environmental and genetic factors, and efficient modalities of supportive care that improve patient survival and enhance quality of life.

Myeloproliferative Disorders: Biology and Management
Edited by:
Richard T. Silver, MD; Ayalew Tefferi, MD

October 2007/240 pp., illus.
ISBN: 9781420061628/$161.96**
CRC Press: 800-272-7737

Myeloproliferative disorders, written by international renowned experts in the field, examines:
– New and developing diagnostic protocols and algorithms and supportive care regimens
– The evolution and classification of recent myeloproliferative disorders
– Advancements and the implications arising from clinical care and practice
– The activating JAK2V617F developed in a chapter by top experts
– The overlap between myeloproliferative disorders and myelodysplastic syndromes
– The importance of histopathology and cytogenetics on understanding these diseases

With the recent discovery of JAK2 mutations in myeloproliferative disorders, medical science has taken a revolutionary stride forward toward understanding the pathogenesis of these diseases. This new advancement translates not only to a more rapid and reliable diagnosis, but also allows groundbreaking research into the development of new therapeutics. Written in an easy-to-follow text myeloproliferative disorders gives the practicing clinician a single source answer to classification, diagnosis, management, and recent advances in this disorder.

**All prices are in US dollars.
Highlights of Latest Literature in MDS

Listed below are citations of some new publications relevant to MDS (pathogenesis, clinical characterization, management, etc.). To access the complete article log on to www.pubmed.gov.

MDS OVERVIEW AND PERSPECTIVES:

The article provides perspective on deleterious effects of chronic RBC transfusions and shows that ESA treatment provides efficacious alternative with favorable safety profile in low/int-1 risk MDS.

DIAGNOSIS AND PROGNOSIS:

The study confirms the difference in survival and leukemia free survival between patients with RA/RARS vs. RCMO/RCMD-RS. Additionally the multivariate analysis revealed negative impact of Hb < 10g/dL, neutrophil < 0.5×10⁹ and platelets < 50×10⁹ on survival.


A population-based cancer registry study for incidence of MDS within the state of Connecticut, USA, shows nearly 3 times higher incidence of MDS than expected near Western border of the state. This is the first evidence of clustering in incidence of MDS.


The study highlights deleterious effects of chronic RBC transfusions and suggests that serum ferritin levels exceeding 1000 ng/mL could cause end-organ damage (cardiac and liver toxicity) leading to mortality.


A review of literature showed that prior to any treatment of MDS, a median rate of thrombocytopenia was 65%, which seems to be paralleled by 67% detection rate reported at authors’ institution at referral with preponderance seen in Int-2/high risk categories.


The study identifies a niche for ATG treatment in MDS.

PATHOBIOLOGY:

Purified marrow CD34(+) cells from MDS patients when induced to undergo megakaryocytic differentiation, underwent apoptosis without Caspase 3 activation, but demonstrated mitochondrial apoptotic changes including cytochrome c release. In contrast, matured normal megakaryocytes manifested caspase 3 pathway of apoptosis.


The CD34(+) CD38(-) Thy1(+) cells bearing 5q- abnormality specifically appear to have elevated expression of BMI1 and down regulation of CEBPA as compared to normal counterparts in MDS patients with 5q- karyotype.


The studies shows that lenalidomide specifically inhibited growth of erythroblasts with 5q- karyotype as compared to those without cytogenetic abnormality.

Now Available From The Foundation

We have assembled a listing of insurance and drug reimbursement resources for MDS patients. It is important to know that there is support for those who cannot afford medicine or other healthcare costs. We hope this new resource will be beneficial in helping you with your medical needs.

This guide to assistance programs in the United States is available for download from the Foundation’s website or can be ordered in booklet form upon request.

Blood & Marrow Transplant News

Blood & Marrow Transplant Newsletter

published four times annually by BMT InfoNet.

To subscribe, contact:

BMT InfoNet
2900 Skokie Valley Road, Suite B
Highland Park, IL 60035
Toll free: 888-597-7674
Tel: 847-433-3313, Fax: 847-433-4599
E-Mail: help@bmtinfonet.org
Web: www.bmtinfonet.org
MDS Foundation Publications

Patient Information & Educational Materials Available from The MDS Foundation

- The MDS News
- MDS Essentials: The Foundation’s E-Newsletter
- Patient Diary

- Understanding Myelodysplastic Syndromes: A Patient Handbook
- Transfusion-Dependent Iron Overload and MDS: A Handbook for Patients
- Insurance and Reimbursement Resources for MDS Patients
- Emerging Treatment Options for Adult MDS: A Clinical Perspective
- Your Journal: Learning About Myelodysplastic Syndromes (MDS) Supported by a grant from Celgene Corporation.
- PBS Program — (Videotape) Healthy Body, Healthy Mind: Learning About Myelodysplastic Syndromes
- PBS Program — (DVD) Healthy Body, Healthy Mind: A Menace in the Blood
- Understanding Myelodysplastic Syndromes: A Patient Handbook

All of these materials are available free of charge from the Foundation.

* The MDS Patient Handbooks will soon be available in the following languages: Arabic, Dutch, Swedish.

The Iron Overload booklets will soon be available in the following languages: Arabic, Turkish

MDS Handbooks Now Available in Multiple Languages

- Understanding Myelodysplastic Syndromes: A Patient Handbook

  a. English
e. Hungarian
i. Portuguese
b. Czech   f. Italian  j. Russian
c. German  g. Japanese  k. Spanish
d. Greek   h. Polish  l. Turkish

Transfusion-Dependent Iron Overload and MDS: A Handbook for Patients

a. English
e. German
i. Portuguese
b. Czech   f. Greek  j. Polish
c. Dutch  g. Hungarian  k. Russian
d. French  h. Italian  l. Spanish

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b. Czech   f. Greek  j. Polish
c. Dutch  g. Hungarian  k. Russian
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The MDS Foundation is very grateful for the heartfelt support of its donors. Our work as a non-profit organization depends on public funding and we hope that you include us as one of the worthy charities that you support this year. We have enclosed a pre-addressed contribution envelope to make it easier. You will receive an MDS Foundation enamel lapel pin in appreciation of your donation.

All donations are tax-deductible.

A Living Endowment

Many families are affected by living with the reality of MDS. There is an extraordinary way to contribute to the MDS Foundation and support our mission of working as a resource for patients, families, and healthcare professionals.

A commitment to donate to the Foundation on occasions of loss, birthdays and anniversary remembrances can be made. Honor your friends or family members on these occasions with a donation, and The MDS Foundation will send an acknowledgment to the recipient, recognizing the occasion.

A Living Endowment donation has been made in honor of:

Jeff and Mei Sze Greene’s Wedding

This donation has been submitted by:

Steve Smotrich and Ros Westlake
Stockton, NJ

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The MDS Foundation relies entirely on gifts and membership fees to further its work. We would like to acknowledge the generosity of the following individuals and organizations that have recently provided gifts to the Foundation:

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In memory of Dr. Jerome Ferber
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32
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38
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If you would like additional information, please contact us at:
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36 Front Street, P.O. Box 353
Crosswicks, NJ 08515
Phone: 800-MDS-0839, Fax: 609-298-0590
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About the Foundation

The Myelodysplastic Syndromes Foundation was established by an international group of physicians and researchers to provide an ongoing exchange of information relating to MDS.

Until the Foundation was set up, no formal working group had been devoted to MDS. During the past decade we have conducted nine international symposia—in Austria, England, the United States, Spain, Czech Republic, Sweden, France, Japan, and Italy. The Tenth International Symposium is being held May 6–10, 2009 in Patras, Greece.

A major Foundation effort is our international information network. This network provides patients with referrals to our Centers of Excellence, entry into available clinical trials, sharing of new research and treatment options between physicians and researchers, and extension of educational and emotional support to physicians, nurses, patients, caregivers, and others working with MDS patients.

In response to the needs expressed by patients, families, and physicians, we have established Patient Advocacy Groups, research funding, and physician education.

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Our Website

The MDS Foundation webpage is for healthcare professionals, patients, and other interested people. The Professional Forum and the Patient Forum are integral parts of our website.

The website is constantly being updated to better serve the needs of our patients, their families, and the physicians who treat them. Please visit us at www.mds-foundation.org.